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Stigma: still an important issue for adults with asthma

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Abstract

Psychosocial issues are recognized as important in the management and care of people with chronic illness, including asthma. There is limited research specifically examining the impact of stigma on people living with asthma, but the few studies that do exist have found that stigma is associated with higher morbidity. Our hypothesis is that the stigma felt by people with asthma creates a barrier to effective self-management practices (which work toward improving asthma control). A cycle of interrelated psychological and physical health factors may emerge, making asthma self-management harder to address. The objective of this study was to determine whether adults with asthma experience feelings of stigma due to their condition and, if so, how this effects their asthma self-management. A Web-based survey using accepted measures of asthma control and stigma was designed and implemented. A total sample of 72 participants was obtained using a snowball recruitment technique. Results demonstrated a positive and significant relationship between asthma control and feelings of stigma, suggesting that people with higher asthma morbidity feel higher levels of stigma. Further research into the impact of stigma on asthma patients is required to further enhance our understanding of patients' self-management practices and to inform future strategies.

Keywords

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Abstract

Psychosocial issues are recognized as important in the management and care of people with chronic illness, including asthma. There is limited research specifically examining the impact of stigma on people living with asthma, but the few studies that do exist have found that stigma is associated with higher morbidity. Our hypothesis is that the stigma felt by people with asthma creates a barrier to effective self-management practices (which work toward improving asthma control). A cycle of interrelated psychological and physical health factors may emerge, making asthma self-management harder to address. The objective of this study was to determine whether adults with asthma experience feelings of stigma due to their condition and, if so, how this effects their asthma self-management. A Web-based survey using accepted measures of asthma control and stigma was designed and implemented. A total sample of 72 participants was obtained using a snowball recruitment technique. Results demonstrated a positive and significant relationship between asthma control and feelings of stigma, suggesting that people with higher asthma morbidity feel higher levels of stigma. Further research into the impact of stigma on asthma patients is required to further enhance our understanding of patients' self-management practices and to inform future strategies.

Key Words: asthma, stigma, chronic disease, self management, patient education

Asthma is one of the most common chronic conditions in Australia.[1] It is distinguished by recurrent attacks of breathlessness and wheezing due to inflammation of the air passages in the lungs.[2] Australia's prevalence rate for asthma is 10%, and the mortality rate (cause of death for 411 Australians in 2009) is high by international standards.[3] Asthma ranks fourth in chronic disease prevalence among Australians, after hypertension (16%), arthritis (15%), and long-term mental health conditions (11%), with diabetes rounding out the top 5 (4%).[4]

Chronic diseases impose a substantial burden on the health system and contributed 82.5% of the total recurrent health expenditure in Australia in 2000-2001.[5] A key feature of living with chronic disease is the need for patients to "self-manage": to treat and, where possible, manage risk factors; to adhere to medication regimens; and to access health services to control their condition.[6,7] Despite the evidence of the benefits of asthma self-management (particularly tailored self-management education) for asthma control,[8,9] the uptake of self-management strategies is poor in Australia [3,8] and internationally.[10,11] One proposed reason for the low uptake of self-management strategies is that they are designed and driven by health professionals using traditional medical or educational approaches.[12,13] The patient perspective—their lived experience—should also be valued and understood to better engage patients as active participants in their health care.[14-17] The poor translation of knowledge (the purpose of patient education) into practice (and better asthma control) suggests that there are other factors, such as psychological factors, that influence asthma patients' perceptions of their condition and, thus, their self-management behavior. This article considers perceptions of stigma that impact self-management practices of people with asthma.

Asthma and Stigma

Psychosocial factors have long been associated with asthma[18-20]. Now refuted as one of the potential *causes* of asthma[21,22], psychological determinants were the focus of research attempting to explain the etiology of asthma for many years in the early 1900s.[23,24] Historically, asthma was viewed as a result of nervousness and hysteria, and the disorder was perceived as a symptom of mental unrest and psychoneurosis.[25,26] It is perhaps not surprising then that stigma (the negative evaluation of an individual based on perceived undesirable attributes[27]) has been associated with asthma for many years.[28] The work of researchers such as Sibbald and colleagues [24,29] and Snadden and Belle Brown [28,30] examined the experience of stigma in asthma patients over 2 decades ago, with the former in particular identifying issues such as nondisclosure, self-blame, and embarrassment over medication use in public.[24,29]

Surprisingly, since that time, there has been limited research specifically examining feelings of stigma among people living with asthma The few studies that have been conducted have found stigma to be associated with poor asthma control.[18,23,29] Of concern are findings from a recent European study,[31] in which 22.5% of participants (230 of 1022) expressed feelings of stigma regarding the taking of asthma medication in public, perhaps indicating that little has changed on this aspect of asthma-related stigma. The media potentially also perpetuates the social stigma of asthma. A recent content analysis of US newspapers found more than 28% of articles contained a stigma cue, serving to isolate and shun people with asthma,[32] and a content analysis of 66 US movies found that of movies showing asthma scenes, more than 17% portrayed characters with asthma as "wimps" or "social outcasts."[33]

Based on this paucity of information in the recent literature, we believe that the issue of stigmatization and the person with asthma warrants further investigation. The purpose of

this article, therefore, is to reinstate a critical awareness and understanding of the effects of stigma, which may be a barrier to effective asthma self-management. If asthma control is affected by feelings of stigma, research insights may inform or enhance current self-management education approaches. If multidisciplinary asthma educators are aware of the effects of stigma on patients' perceived ability to effectively self-manage, they will be better positioned to tailor their approach to patient self-management education and support. We sought to measure the extent of feelings of stigma in a population of adults with asthma using a cross-sectional research design.

Method

Following ethics approval from the university's Human Research Ethics Committee, a 47-item Web-based survey was implemented using the survey provider Survey Monkey (www.surveymonkey.com.au). The survey was emailed to a convenience sample of 135 individuals whose details were available to the authors from their involvement in previous asthma research,[34,35] recruited through the Australian Electoral Role and membership of an online asthma newsletter. While some email addresses were invalid or incorrect (n = 24), successful recipients were asked to forward the survey link to other adults with self-reported asthma (snowball sampling[36]). A participant information and consent screen was viewed, and informed consent was obtained when participants clicked a button to indicate they had read the information and wished to begin the survey. The survey remained "live" for 5 weeks during April to May 2012.

Survey Tool

Measures of asthma control were obtained using the Royal College of Physicians (UK) "3 Questions" (RCP3),[37] the most widely used measure of asthma control in the United

Kingdom (see Table 1). This measure was chosen since there is no universal agreement as to the best standardized method to assess asthma control (the Global Initiative for Asthma, in fact, lists 4 reliable tools[38]) and because it has been evaluated against validated tools, such as the Asthma Control Test[39] and the Asthma Control Questionnaire,[40] demonstrating both clinical accuracy and easy practical use.[41,42]

Since there is no existing tool designed to specifically measure asthma-related stigma, measures of stigma for this study were obtained by using 19 items of the Stigma Scale for Mental Health (originally 28 items, 4 items were omitted as they were perceived to be repetitious and 5 were omitted due to the specific relevance to mental health).[43] This stigma scale, originally designed to reflect the lived experience of stigma in mental health patients, contained 3 factors (subscales) underlying the complexity of stigma: (*a*) disclosure by the patient about his or her condition, (*b*) discrimination felt by the patient as a result of the condition, and (*c*) perceived positive aspects of the diagnosed condition. Additionally, the Stigma Scale for Mental Health was of particular interest to us because it has also been tested against the validated Self-Esteem Scale,[44] confirming a negative relationship between self-esteem and feelings of stigma. This was an important feature to recognize in the context of asthma self-management due to the role of self-esteem in the development of self-efficacy.[45]

Finally, in addition to the RCP3 survey questions and the 19-item stigma-related questions in the online survey, participants were asked questions about their physical and mental health. These physical and mental health questions were obtained by using the Short Form 12 Item Health Survey Questions (SF-12).[46] The authors added a further 3 items regarding asthma severity; the remaining 10 of 47 items collected demographic data.

Measures of asthma control, stigma, physical and mental health

Asthma control, using the RCP3 tool, was assessed according to the participant responses to the survey questions (where 3 responses of "Yes" = daily symptoms, high morbidity; 2 = symptoms once or twice per week, medium morbidity; 1 = symptoms once or twice per month, low morbidity; and 0 = no symptoms, under control).

Stigma was assessed using the 19-item stigma scale. The Likert-type scale scores were summed to provide an overall stigma score that was included in the analyses (Cronbach's α = .890).

Physical and mental health scores were calculated using the SF-12 scoring demonstration (http://www.sf-36.org/demos/SF-12.html). Scores of 50 were considered "normal." Scores of 40 or less indicated poor health, whereas scores of 60 or more indicated good health.

Data Analysis

Statistical analyses were carried out using SPSS version 19.0 for Windows 2007. Analysis of variance (ANOVA) was performed to analyze whether perceptions of stigma were different depending on asthma control (high morbidity, medium morbidity, low morbidity, and under control). Then ANOVA was performed to determine whether physical and mental health scores differed between morbidity categories. Post hoc analyses, using Bonferroni correction (α of .05), were used to specify the pattern of relationship between the variables of interest (asthma control and stigma; and stigma and asthma control). Pearson's correlation was

performed to analyse the strength of the association between stigma and physical and mental health scores.

Results

Participant Characteristics

A total of 72 participants (19 male, 53 female) with a mean age of 33 years (SD = 14.8) completed the survey. The sample was reflective of an educated, homogenous population of adults with asthma. Most (n = 56, 78%) were born in Australia and spoke English at home (n = 68, 95%), with 49% (n = 35) having university qualifications and 47% (n = 34) having a combined household income of more than AU$70 000 (approx US$72 200).

Nearly half (n = 34, 49%) of the participants had been living with asthma since childhood, and a further 38% (n= 26) had been diagnosed more than ten years ago. Hospitalizations in the previous twelve months due to asthma (acute exacerbations) occurred at least once for 14% (n= 10) of the sample.

Morbidity

Participant responses to the RCP3 questions are reported in Table 1. Overall, 23% of participants' asthma was under control. The largest proportion of the sample (35%) had high morbidity, whereas 42% had medium morbidity (see Table 2).

Table 1 Royal College of Physicians 3 Questions Responses

	In the last month:	Frequency	Valid Percentage (%)
1	Have you had difficulty sleeping because of asthma	Yes 32	46.4

	symptoms (including cough)?	No 37	53.6
2	Have you had your usual asthma symptoms during the day (cough, wheeze, chest tightness or breathlessness)?	Yes 51	73.9
		No 18	26.1
3	Has your asthma interfered with your usual activities (e.g.: housework, work, school, etc.)?	Yes 29	42.0
		No 40	58.0

Table 2 Participants' Levels of Asthma Control as per GINA Guidelines.

Category	Description of Common Characteristics	Percentage of respondents in sample
Under Control	No nocturnal waking	23
	No activity limitation	
	Symptoms experienced not more than twice per week	
	Reliever medication used not more than twice per week	
	Normal lung function, no exacerbations	
Medium Morbidity	Some nocturnal waking	42
	Some activity limitation	
	Symptoms experienced more than twice per week	
	Reliever medication used more than twice per week	
	80% of predicted or personal best lung function, some exacerbations over a year	
High morbidity	Three or more of the above features experienced in any one week.	35

Stigma

Only 9 respondents reported feeling no stigma (14%). The majority of respondents (n = 33, 51%) reported low stigma. Medium levels of stigma were reported by 14 respondents (21%) and high levels by 9 respondents (14%). Of the 19 stigma items, the most frequent items

answered in the affirmative were "Having asthma has made me a more understanding person" (n = 24, 32.5%); "I would have had better chances in life if I had not had asthma" (n = 15, 23%); and "Having had asthma makes me feel that life is unfair" (n = 8, 11%). These responses span all of the subscales, positive aspects, disclosure, and discrimination, respectively.

Physical and Mental health Scores

While 72 participants completed the survey overall, only 61 provided data on physical health (on a scale of 24 to 60, mean = 47) and mental health (on a scale of 21 to 65, mean = 49) scores. Fourteen participants (23%) recorded clinically low physical health scores (≤40 on SF-12). A different 14 participants (23%) recorded clinically low mental health scores (≤40 on SF-12). Only 3 participants (5%) recorded *both* clinically low mental *and* physical health scores. There were no participants who recorded *both* clinically high (≥60 on SF-12) mental *and* physical health scores.

Stigma and Morbidity

ANOVA analyses indicated that feelings of stigma differed significantly between the 4 asthma morbidity groups, $F(3, 61) = 3.46$, $P = .02$, $\eta 2 = .15$. The post hoc tests indicated that participants reporting high morbidity (mean = 47.52; SD = 13.42) had higher feelings of stigma than those who reported low morbidity (mean = 38.29; SD = 8.53; $P = .04$). Furthermore, participants reporting high morbidity (mean = 47.52; SD = 13.41) also appeared to feel more stigmatized than those who considered their asthma to be "under control" (mean = 38.47; SD = 7.25), but this trend did not reach statistical significance ($P = .07$). No other significant differences emerged from the Bonferroni comparison.

Relationships between Stigma and Physical and Mental Health

The ANOVA analyses (Bonferroni) indicate that individuals experiencing high asthma morbidity had poorer overall physical health, $F(2, 57) = 5.48$, $P = .007$, $\eta 2 = .161$, than those with medium or low morbidity or well-controlled asthma. The Pearson correlation also revealed negative relationships between stigma and physical health score, $r = -.41$, $P = .001$ ($r2 = .17$), and stigma and mental health scores, $r = -.23$, $P = .045$ ($r2 = .05$), such that those participants reporting higher levels of stigma were more likely to report poor physical and/or mental health.

Discussion

In this study population, our results first confirm that the majority of adults with asthma have poor control over their chronic condition—a finding consistent with many other studies.[8,47,48] Our results also confirm that poor asthma control (high morbidity) is significantly associated with feelings of stigma. A similar finding was reported in a study of patients with irritable bowel syndrome, where individuals with greater levels of "flare ups" reported greater levels of perceived stigma.[49] The patient's reaction to stigma (such as nondisclosure, denial, or trying to be "normal") can be detrimental to the long-term health outcomes of people with chronic illness.[50] Furthermore, the potential negative effects on the patients' levels of self-efficacy and ability to effectively self-manage is cause for concern.

In a study of stigma and hepatitis C,[51] stigma was found to create barriers to accessing health services and social support, whereas a study examining stigma and epilepsy[52] also highlighted barriers to social support and the detrimental impact on self-efficacy and self-management.

These examples illustrate the compounding effects of stigma in people with chronic illnesses, which include psychological distress, depression, anxiety, and increased risk of advanced disease.[53] Our results support these findings, demonstrating a relationship between stigma and mental health. Psychological conditions such as depression and anxiety are common comorbidities associated with asthma, and many studies underscore the detrimental impact they have on patients' adherence to self-management strategies.[54-57]

Our results indicate that stigma is still an issue for adults living with asthma. Other studies have determined a negative relationship between perceived levels of stigma and self-efficacy.[58,59] If this is also true for asthma patients, then asthma-related stigma is potentially an important barrier to effective self-management practices—and an important factor for asthma self-management educators to be aware of in the context of supporting patients' efforts toward asthma control.

Physical health outcomes were also found to be negatively associated with stigma in our study. People living with asthma are known to have poorer quality of life than those without asthma, having an impact on overall physical functioning as well as the ability to fulfill social roles.[60] Sturdy and colleagues have suggested that severe asthma may "give rise to psychosocial or health behavior problems which reduce the quality of care . . . setting into motion a vicious spiral of increasing severity interacting with psychosocial adversity."[61(p1038)] Insights from this study identify stigma as a common variable that affects both physical and mental health status and is interrelated with poor asthma control. Redressing the impact of stigma could therefore have beneficial health outcomes for people living with asthma.

Implications for Practice

Stigma has harmful implications for patient self-management due to its effect on self-efficacy and the obstacles it places on patients' social relationships and access to health care. The unfortunate implications of this are increased morbidity and a reduced quality of life.[62]

To reduce stigma, strategies such as peer support and social marketing are well placed to address some of the problems highlighted in this article. Peer support programs provide emotional and social support for patients and have a demonstrated capacity to enhance self-efficacy and promote positive health outcomes.[63,64] On a broader scale, the consumer-oriented approach of social marketing [65] provides an effective framework from which to overcome systemic effects of stigma. As has been attempted for mental health stigma, for example,[66] social marketing has the capacity to target multiple audiences (patients, health care providers, and the general public) to re-educate and better inform people of the reality of chronic disease.

Stigma also has implications for the way in which health professionals engage and communicate with adults with asthma. There is evidence to suggest that patients anticipate stigmatizing treatment from within health care settings.[62] They therefore avoid accessing services, which affects their symptom control and quality of life.[62,67] Health professionals should be aware of the potential barrier that perceived stigma creates for patient health care access as well as being mindful of their individual approach to patient care. Asthma self-management education demonstrates clinical improvement in asthma outcomes[9]—educators and education programs that build self-efficacy through encouragement, reinforcement, reassurance, and feedback are among the most effective.[68,69] It is these same elements

through cognitive behavioral interventions that reduce psychological comorbidities associated with asthma.[54,57] Further understanding of psychosocial factors for patients, including feelings of stigma, could substantially influence the patient–provider relationship to better reflect the lived experience of adults with asthma.

Implications for Research

While various psychosocial aspects of the person living with asthma (eg, panic and fear) have been given reasonable attention from researchers and clinicians,[70,71] research into the impact of stigma seems to have lapsed somewhat over the past 2 decades. Since we have demonstrated that there is a relationship between asthma control and stigma, then a repeated-measures survey or longitudinal design may provide data able to discriminate elements of causation. We also suggest that the relationship between asthma control and stigma is potentially bi-directional and that further inquiry is required. For example, obvious symptoms of asthma and public exacerbations (degree of asthma control) may increase perceived feelings of stigma—feeling stigmatized may deter public medication use and harm asthma control.

Further research is also needed to explore the extent and effect of stigma in people living with asthma. While traditionally, psychological or help-seeking approaches have been used to explore the role of stigma in people with chronic diseases, including mental health disorders,72 recent calls for the application of social marketing to address stigma have also occurred.[73,74] The four "Ps" of social marketing are a useful framework that could potentially help articulate and address stigma as a barrier to effective asthma self-management. By understanding the target audience's perceptions about the product (asthma self-management) and price (stigma, for example), social marketing can potentially offer solutions after

consideration of place (such as health care settings) and promotion (such as social network, or media campaigns).

The same principles can be applied to research investigating different forms of social support such as online blogs, peer support groups, social activities, or one-on-one support from health professionals. Consumer-orientated opportunities that provide relevant and accessible social support require further exploration to redress issues of isolation and low self-efficacy.

Limitations

In this preliminary research, the sample size of our study limits the generalizations we can make in regard to the impact of stigma and the interrelationship between asthma control and stigma. Intuitively, however (and despite the lack of a validated measure of asthma-related stigma), the results lend themselves to further investigation. Our cross-sectional design was limited in that the nature of asthma control/exacerbations is fluid for most patients (depending on seasonality, for example). While participants reported to have been provided with an asthma *diagnosis*, asthma severity, including medication use, was not validated. Finally, our sample was homogenous by nature reflecting a white, Anglo-Saxon, educated middle class; vulnerable groups such as lower socioeconomic populations, older adults, or people of Aboriginal and Torres Strait Islander descent were not captured by this recruitment method. These groups are also likely to experience stigma from other sources,[72] not just their asthma, making them a complex yet highly important target for future research.

There are other demographic limitations to be noted in this study. It is possible that the online "snowball" recruitment method extended to overseas participants, though we cannot confirm or measure this. The very small proportion of males in the sample precludes us from making

any specific observations about similarities or differences between genders. Also, our study design assumed participants had competent levels of health literacy and computer skills.

Conclusion

The results of this study reveal some clear trends regarding the association of stigma on the overall health of people with asthma. We found that high morbidity is associated with greater feelings of stigma although the direction and nature of this relationship is unclear. Furthermore, our results demonstrate a concerning relationship between stigmatization and poor physical and mental health.

Further research is needed to fully understand the consequences of stigma for people with asthma. With greater understanding, health care providers will be better able to: design campaigns to reduce stigma, better advocate for those with chronic conditions, and devise better self-management programs that take into consideration the beliefs and perceptions of individuals affected.

The translation into practice therefore must encapsulate social and psychological aspects of patient care that compliment medical treatment. Social/peer support and tailored self-management education can help redress issues of stigma and build a supportive environment for people with asthma.

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